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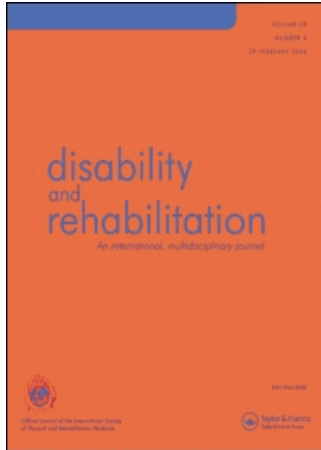
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## CLINICAL COMMENTARY

# Integrated care for MS patients

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### Abstract

**Purpose.** The problem of complex healthcare to MS patients, together with the rising prevalence of MS and escalating costs, has caused healthcare policy makers to consider innovative approaches to controlling costs and improving the quality of care. An integrated care approach may provide a means for better coordination and delivery of care. The aim is to review recent integrated care initiatives and their significance for MS patients.

**Method.** A literature search was conducted to trace relevant literature on integrated care for MS patients published between 1995 and 2003.

**Results.** Although integrated care appears to offer potential for eliminating fragmentation and discontinuity in healthcare for MS patients, there are few published studies which have evaluated its implementation with MS patients.

**Conclusions.** Even though the potential advantages of integrated care are well known, the applicability of this approach for MS patients has still to be demonstrated.

**Keywords:** *Multiple Sclerosis, integrated care, effectiveness, delivery of healthcare*

### Introduction

The rapid rise of chronic diseases represents one of the major challenges to healthcare policy makers. Chronic diseases are now the major cause of death and disability worldwide, and increasingly affect people from developing as well as developed countries [1]. One of these diseases is Multiple Sclerosis (MS). MS is a chronic, disabling neurological disorder affecting 100–120 people per 100,000 population in geographical high risk areas such as Canada and the northern parts of the United States and Europe, including The Netherlands. It is expected that in the 20 years to come, the population of MS patients in The Netherlands will increase by almost 14% [2]. MS primarily affects adults, with an age of onset typically between 20 and 50 years, and is more common in women than in men. The cause of this disorder is not known, but environmental, viral, and genetic factors are thought to play a role. MS symptoms are variable and differ from one person to another. The most common symptoms of MS are fatigue, bladder and bowel problems, spasticity, vision disturbance, mobility and sensory problems.

The delivery of healthcare to MS patients is characterized by the involvement of a wide range of services which provide several strategies to help combat many of the health problems of MS patients. However, the coordination and continuity of care delivered by those services often seems seriously deficient; the services are fragmented, communication is poor, goals are often not shared, and there is an unacceptable delay in the onset of these services once they have been recommended [3–4]. The problem of complex healthcare, together with the rising prevalence of MS and as a consequence escalating costs, has caused healthcare policy makers to consider innovative approaches to controlling costs and improving the quality of care.

One of these innovative approaches is integrated care. Integrated care emerged in the United States in the 1990s and is described as ‘inter-sectoral cooperation (coordination/networking) between care providers from both the health and social care sector in order to deliver seamless/continuous care to people with multiple needs, as a remedy to fragmentation and discontinuity’ [5]. It is required when the services of separate agencies and individual professionals

do not cover all the demands of the multiple problem service users. Also other concepts are used to describe organizational changes in healthcare, like transmurial care, multidisciplinary care, shared care and disease management. The concept of integrated care however is more comprehensive and can be seen as an umbrella term for all its variations in practice [6].

The aim of this study is to explore the value of integrated care for MS patients. For this purpose, the criteria that guide the selection of diseases to be managed by means of integrated care will be specified. Furthermore, an overview of the literature on integrated care initiatives in this field will be presented.

## Methods

In order to explore the recent integrated care initiatives for MS patients, relevant databases (Medline, Embase and Cinahl) were initially searched on the keywords 'multiple sclerosis' and 'integrated care', 'continuity of care', 'satisfaction', 'efficient healthcare' and 'effective healthcare'. Since the initial search provided unsatisfactory results, the search was expanded with other related keywords such as 'multidisciplinary', 'multidisciplinary care', 'shared care' and 'disease management'. Literature published between 1995 and 2003 was reviewed to identify recent initiatives in integrated care for MS patients. The literature search concentrated on integrated care initiatives across different healthcare settings.

## The value of integrated care for MS patients

Concerning integrated care, it is well known that the provision of healthcare by a coordinated team of professionals always has been assumed to be valuable [7]. Integration should occur across time and healthcare settings, including primary healthcare, care of a specialist, and inpatient care [8]. An interdisciplinary approach is needed for comprehensive assessment, treatment, and management in order to be successful in accomplishing the following goals [8–9]:

- (1) Reduction of fragmentation and discontinuities in healthcare;
- (2) Improvement of user satisfaction and outcome;
- (3) Delivery of efficient and effective healthcare.

To find out whether integrated care is advisable in case of MS, the above mentioned criteria that guide the selection of diseases to be managed by means of integrated care will be specified.

## *Reduction of fragmentation and discontinuities in healthcare*

The essence of integrated care is that individuals receive the care services they are in need of. It is care which appears seamless to the service recipients and not to be interrupted by service gaps, overlaps fragmentation or lack of cooperation [10]. If MS patients fail to receive the care they need, one can suggest that also many of the patients' needs are unmet [3,11].

Although several authors state that continuity of care for MS patients is seriously deficient in fact most evidence in this area is anecdotal and few studies have systematically and objectively investigated or confirmed these shortcomings [3–4,12]. To the best of our knowledge, only four studies have evaluated the delivery of inadequate services and its consequences (amount of unmet health needs) [3,13–15]. Table I presents an overview of these four studies.

The study of Freeman and Thompson [3] indicates that, despite a shift of emphasis from hospital to community care and the establishment of standards of care for MS, many people with moderate (39%) or severe disability (12%) fail to receive community services. The study of Kersten et al. [13] reported an average of 2.9 unmet needs in MS patients. The unmet needs were related to health, personal objectives, social life, accommodation, finances, education, employment, leisure, transport and access. Somerset et al. [14] show in their study that three-quarters of the MS patients state that they lack MS-related advice (advice relating to urinary problems, diet, beta-interferon treatment and appropriate exercise). Oeseburg et al. [15] report that MS patients had an average of 1.4 unmet expressed needs.

## *Improvement of user satisfaction and patient outcome*

Other reasons for a disease to be managed by means of integrated care are user dissatisfaction with the care provided and a poor patient outcome. Studies on the satisfaction of care to MS patients are limited, despite the growth of patient satisfaction research over the last 20 years [16]. Gottberg et al. [17] assessed patient satisfaction in 26 MS patients. Satisfaction on various dimensions of care for MS patients (art of care, technical quality of care, accessibility/convenience, cost of care, availability, continuity, efficacy/outcome of care, participation in planning care and in planning training programme) showed that the MS patients were most satisfied with care provided by the same staff (continuity), kindly provided treatment and access to health-related transportation services. MS patients were least satisfied with the provision of adequate training and

Table I. Studies presenting (the consequences of) discontinuity and fragmentation of healthcare for MS patients.

Author(s)	Objective of study	<i>n</i>	Method	Results
Freeman and Thompson, 2000 [3]	To investigate the level of services and home modifications received by MS patients	150	Interview study using a structured questionnaire to determine current use of outpatient and community services and the home modifications in place	Some 39% of MS patients with moderate and 12% with severe disability failed to receive community services
Kersten et al. 2000 [13]	To develop an international services and needs assessment instrument (SUN) for MS patients and their carers in order to identify unmet needs related to health, personal objectives, social life, accommodation, finances, education, employment, leisure, transport and access	137	Interview study using an adapted version of a previously validated needs assessment questionnaire	MS patients reported on average 2.9 unmet needs
Somerset et al. 2001 [14]	To determine the healthcare preferences of people with MS	318	Use of a postal questionnaire to explore preferences of people with MS (that is, among other things, their actual and desired contact with healthcare professionals and their unmet information needs)	Three-quarters of the sample state that they lack MS-related advice in at least one area. Advice relating to urinary problems was required by almost a third of people in the study sample. A similar number would like to know more about diet and about beta-interferon treatment. Some 41% of all respondents would like information about appropriate exercise
Oeseburg et al. 2004 [15]	To reduce the discrepancies between the MS patients' needs and use of healthcare services	40	Use of a postal questionnaire to identify subjective and expressed healthcare needs and use of healthcare services	At base line the 40 MS patients reported 57 expressed needs. Information (need for information about the disease, prognosis, and available services) and service needs (medical care and types of therapy) were most reported

participation in the planning process of care. Kroll et al. [18] determined the overall satisfaction with primary care among MS patients. The authors demonstrate in their study that MS patients ( $n = 70$ ) are satisfied with their primary care doctors and the primary care services they receive.

Concerning patient outcome, one of the most important outcomes in MS patients is Quality of Life (QoL). It is widely known that MS has an early and profound impact on QoL and since there is no known cure for MS, one of the main goals of interventions in common is to optimize QoL. From

literature it appears that QoL is essential in measuring effects of interventions, as traditionally used measures of medical outcome such as morbidity and mortality do not sufficiently capture the full impact of (medical) interventions, especially in case of chronic diseases [19–21].

#### *Delivery of efficient and effective healthcare*

The high costs of healthcare for MS patients are a third reason for management of MS according to the principles of integrated care. Every MS patient will

use healthcare and other services more or less during their entire life span. At least half of all patients are significantly dependent upon others for mobility and other activities, and patients with MS aged under 65 years are major users of long-term care and support services [22].

Although it is known that MS patients make a particularly heavy demand on health services, detailed information about the extent, type and content of the demand for healthcare services of MS patients is missing [23]. Information on utilization of medical and social services however is essential for good healthcare planning. Besides, awareness of the costs of healthcare utilization is required with regard to cost containment [24].

From the aforementioned, one can conclude that healthcare for MS patients leaves room for improvement. The presence of unmet needs in MS patients, the major impact from MS on Quality of Life (QoL) and the high costs associated with the disease are important driving forces for changing the provision of healthcare. As mentioned before, integrated care could be the strategy. To explore potential effects of integrated care on certain outcomes, recent initiatives on integrated care (across different healthcare settings) for MS patients are described in the continuation of this paper.

### Recent integrated care initiatives

Table II lists the studies that describe integrated care services for MS patients across different healthcare settings. For each study the table shows the initiative, the authors, the year of publication, the kind of study and any possible effects of the integrated care initiative.

Only two publications on integrated care initiatives across different healthcare settings for MS patients were found [4,25]. The overall aim of the services is to provide comprehensive services to MS patients and their families. As stated, both initiatives deliver multidisciplinary care across different healthcare settings. The interventions not only encompass one aspect of care but combine different elements like medical treatment, rehabilitation and nursing care.

In order to explore the value of the described integrated care initiatives, we looked whether the papers did contain evidence on the effectiveness of the initiative. Although both studies include an evaluation, the quality of the evaluation of Makepeace et al. [25] is arguable because of the limited duration of the study and the absence of a control group.

As mentioned before, integrated care means that a range of professionals from different care sectors must coordinate their work and collaborate with

others to meet the needs of the individual user [10]. However, in both studies nothing is mentioned about a change in (un)met needs or a reduction of fragmentation and discontinuities in healthcare as indicated by MS patients.

### Discussion

In theory integrated care appears to offer potentials for eliminating the fragmentation and discontinuity in healthcare to MS patients; it may bring along several advantages like improved continuity of healthcare, efficiency and effectiveness of healthcare. However, this assumption has been difficult to prove empirically, in the first place as a result of the unclear distinction between the different concepts that describe forms of cooperation between several healthcare workers, e.g., integrated care, shared care, multidisciplinary care, and disease management. Clear definitions of the various concepts are lacking and also possible differences are ambiguous. As a result, concepts used are mixed up, without knowing whether it is applied in the right way. Also in this study other concepts are used (e.g., multidisciplinary care) in order to retrieve collaboration initiatives between the cure and care sector. Besides the use of different concepts, the design and delivery of integrated care in itself often differs per country and depends on the structure of the healthcare system, differences in finance and the variation of providers and services involved [26]. A second reason why the effectiveness of integrated care initiatives has been difficult to prove empirically is the lack of evaluation studies. Only two integrated care initiatives have been found in the literature, taking into account that the evidence of one of the evaluations is weak. Similar outcomes (few empirical studies on the effectiveness of integrated care) are presented in recent studies on the effectiveness of jointly provided health and social services for other target groups. In this respect, Glendinning [9] mentions a study of [27] who conducted a systematic review of research into the effectiveness of jointly provided health and social services. They identified only four studies which met the review's inclusion criteria and even these failed to provide conclusive evidence of the benefits for users of joint working. Also Rosendal [28] conducted a study to gain more insight in the effectiveness of healthcare delivery, provided on the basis of cooperation and coordination between generalists and specialist. However, the concept referred to is related with the concept integrated care, the so-called transmural care is less comprehensive than integrated care since it generally does not include the whole care-process of patients. The conclusion of the authors is that at the time of the study relatively little has been published in The

Table II. Effectiveness of integrated care (across different healthcare settings) for MS patients.

Initiative (author)	Healthcare settings				Quality of evidence
(A)					
Community Multiple Sclerosis Team (Makepeace et al. 2001) [25]	The multidisciplinary team is based in the community and it provides physiotherapy, occupational therapy, social work, counselling and psychological input, with access to other services such as speech and language therapy, podiatry and dietetics as needed. The team has links with MS specialist nurses and neurologists based in the local acute trust.				Cross-sectional design (satisfaction) (CSQ) and one group pretest/post-test design (pre-experimental) (EDSS, FIM, GHQ, NIAF) <sup>1</sup>
Home based care multidisciplinary team (Pozzilli et al. 2002) [4]	The home-based care multidisciplinary team included two neurologists, an urologist, a rehabilitation physician, a psychologist, a physical therapist, a nurse, a social worker, and a coordinator. The team collaborated with the patient, physician, and caregiver.				Prospective randomised controlled trial with a one-year follow-up (EDSS, MMSE, FIM, FSS, STAXI, STAI, CDQ, SF-36) <sup>2</sup>
Initiative (author)	Fragmentation and continuity of care	Patient satisfaction	Quality of Life	Cost-effectiveness	Outcome
(B)					
Community Multiple Sclerosis Team (Makepeace et al. 2001) [25]	Not evaluated	Client Satisfaction Questionnaire	Not evaluated	Comparison of base line contacts over previous six months with contacts over six months with team	<ul style="list-style-type: none"><li>● High level of satisfaction (mean score 26.5, range 10–32)</li><li>● Overall cost saving over the six month period of £5993</li></ul>
Home-based care multidisciplinary team (Pozzilli et al. 2002) [4]	Not evaluated	Not evaluated	SF-36	A cost minimization analysis (only direct costs: Cost of inpatient, outpatient, and home care services, as well as the cost of the home based coordination programme)	<ul style="list-style-type: none"><li>● Improvement in four SF-36 health dimensions: bodily pain, general health, social functioning, and role-emotional (<math>p \leq .001</math>)</li><li>● The costs of home based care was slightly less (822 euros/patient/year) than hospital care, mainly as a result of a reduction in hospital admissions</li></ul>

<sup>1</sup>CSQ, Client Satisfaction Questionnaire; EDSS, Expanded Disability Status Scale; FIM, Functional Independence Measure; GHQ, General Health Questionnaire; NIAF, Newcastle Independence Assessment Form; <sup>2</sup>EDSS, Expanded Disability Status Scale; MMSE, Mini-Mental State Examination; FIM, Functional Independence Measure; FSS, Fatigue Severity Scale; STAXI, State Trait Anger Expression Inventory; STAI, State Trait Anxiety Inventory; CDQ, Clinical Depression Questionnaire; SF-36, 36 item Short Form Health Survey Questionnaire.

Netherlands with respect to the effectiveness of transmural care. The evidence available is not very strong due to the small number of studies published and the poor quality of the study designs. Vondeling [6] also concludes that, although it is generally assumed that integrated care results in increased effectiveness and quality of care while being cost-effective or even cost-saving at the same time, systematic evaluation, including an evaluation of the relative costs and benefits of these arrangements has largely been lacking. Reasons for the lack of evaluations are, among other things, the complexity

of the intervention and the perceived methodological difficulties.

In 2005, Singh and Ham have summarized the evidence for each of the components of integrated care, including the positive effects of integrating primary and secondary care across organizational boundaries [29]. The authors found evidence from 34 systematic reviews, 103 randomized trials, and 21 other studies. Supporting previous evidence, also in this report most studies have investigated the impact of integrated care on diabetes, asthma, depression, geriatric patients and heart failure. From the review

of Singh and Ham, it appears that there is some evidence that integrated care may improve patients' knowledge and satisfaction with care and may improve health resource use and reduce costs too. Also a number of studies suggest that integrated care may improve some clinical outcomes, even though most studies found only few differences between integrated care and usual care. Evidence about the impact of integrated care on quality of care is inconsistent. However, there appears to be a trend towards improved quality of care in integrated systems.

Consequently, even though in writing the advantages of integrated care are well known, the precise applicability for MS patients still has to be identified. First of all, there has to be determined which aspects of care will need specific attention. From the above mentioned it appears that it is unclear how MS patients judge the care provided: Only few studies are aimed at the evaluation of care (fragmentation and discontinuity in healthcare and satisfaction of MS patients). However, implementing a(n) (integrated) healthcare initiative requires understanding of current healthcare issues or shortages. Therefore, a thorough analysis of recent care is desirable: At what points does the care to MS patients differ from the most desired situation and what are the impeding and facilitating factors in order to reach the desired situation? Without an analysis of recent care it is impossible to determine the actions necessary to be taken in order to improve care. Furthermore, a systematic analysis of problems or shortages in the delivery of healthcare also defines the strategy of choice in order to implement the innovation in an organization. The choice will be based, among other things, on the (sub)population(s) and possible factors that impede reaching a certain situation [30].

In conclusion, in order to improve healthcare for MS patients, further research is needed to reveal current healthcare issues. Such evaluations should, besides thorough assessments of (un)met healthcare needs among MS patients, also incorporate coordination and continuity of care delivered by the services involved and communication between healthcare professionals. Although also the costs of integrated care have to be taken into account, we have to bear in mind that the preference of integrated care should be based upon 'quality of life' consideration, rather than on 'costs' consideration.

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